



## INITIATIVES TO HELP ELDERLY PARENTS OF INTELLECTUALLY DISABLED PERSONS

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### INTELLECTUAL DISABILITIES

According to the Diagnostic and Statistical Manual, intellectual disability involves impairments of mental abilities in three areas. These are (1) the conceptual domain (e.g., skills in language, math, reasoning, and memory), (2) the social domain (e.g., interpersonal communication skills and the ability to make and retain friendships), and (3) the practical domain (e.g., the ability to manage personal care, job responsibilities, and money).

### QUESTION

What initiatives have been developed in Connecticut and other states to assist elderly parents of intellectually disabled persons?

### SUMMARY

In Connecticut, the Department of Developmental Services (DDS) has a unit that provides services for DDS clients as they and their caregivers age. However, the unit focuses on the client and does not provide services specifically for the clients' parents, other than respite care, primarily because Medicaid does not pay for these services.

We only found a few initiatives in other states specifically designed to assist elderly parents of intellectually disabled persons. Indiana had a small pilot project to demonstrate how Web-based social

media could be used to bridge informal and formal systems of care supporting adults with intellectual disabilities and family caregivers.

Kentucky adopted legislation requiring its equivalent of DDS to establish a centralized resource and referral center for aging caregivers. But the mandate is tied to the availability of funds and the center has not been established to date.

In 2000, Ohio commissioned focus groups to gain more information about aging caregivers of people with intellectual disabilities and the challenges they face.

In addition to these initiatives, a number of organizations have developed materials to help aging caregivers of people with intellectual disabilities. Examples include [\*Planning for a Good Life\*](#), produced by the ARC of Massachusetts (an advocacy group) and [\*Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities\*](#), published by the Center on Intellectual Disabilities at the University at Albany.

A federal program provides grants to state aging agencies to support a range of caregivers, including those that care for persons with intellectual disabilities under limited circumstances.

## **PEOPLE WITH INTELLECTUAL DISABILITIES – DEMOGRAPHIC CHANGES**

The population of elderly people, including those with intellectual disabilities, is increasing as the “baby boom” generation ages. Moreover, the life expectancy of people with intellectual disabilities has increased due to changes in public policies, improved health care, and better community support services. Although adults with intellectual disabilities still have slightly lower life expectancies than the general population, these persons are living significantly longer than just a few decades ago, and many adults with disabilities can now expect to live as long as the general population. Approximately 75% of older adults with intellectual disabilities reside with their families.

## **FEDERAL PROGRAM**

The federal National Family Caregiver Support Program provides grants to states to fund a range of supports to assist family and informal caregivers to care for their loved ones at home. The following types of caregivers are eligible for services under this program:

1. adult family members or other informal caregivers age 18 and older providing care to individuals age 60 and older or to individuals of any age with Alzheimer’s and related diseases and
2. grandparents and other relatives (not parents) age 55 and older providing care to children under age 18 or adults age 18-59 with disabilities.

Thus, this program could be used to help parents of individuals with intellectual disabilities when their children (1) are age 60 or older or (2) also have Alzheimer’s or a similar disease.

The services offered under the program include:

1. information about available services;
2. assistance to caregivers in gaining access to the services;
3. individual counseling, organization of support groups, and caregiver training;
4. respite care; and
5. supplemental services, on a limited basis.

Further information about the program is available at [http://www.aoa.gov/aoa\\_programs/hcltc/caregiver/index.aspx](http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx).

## **INDIANA**

Hoosier TYZE was a pilot project funded through Indiana University (IU) to demonstrate the role of Web-based social media in bridging informal and formal systems of care supporting adults with intellectual disabilities, elders, and family caregivers. The social media platform provided a vehicle for tasks such as arranging respite, transportation, and other forms of assistance; sharing stories; accessing information sources; circulating written records (with secure and private storage); and giving and receiving emotional support.

The project was administered by the Center on Aging and Community at the Indiana Institute on Disability and Community, IU's School of Informatics and Computing, and the Indiana Family and Social Services Administration. It supported 13 Indiana families to create individualized online family and community networks, supporting their adult members with disabilities in a virtual "circle of care." This system of family supports was designed to demonstrate a role for state government that emphasizes partnerships between family and community systems of informal supports. Further information about the project is available at [https://www.aucd.org/template/news.cfm?news\\_id=8187&id=17](https://www.aucd.org/template/news.cfm?news_id=8187&id=17). An evaluation of the project is currently being completed.

## **KENTUCKY**

Kentucky law ([Ky. Rev. Stat. § 205.470](#)), requires the Department for Behavioral Health, Developmental and Intellectual Disabilities, if funding is available, to establish a centralized resource and referral center designed as a one-stop system to provide aging caregivers with information and assistance with choices and planning for long-term supports for individuals with an intellectual or developmental disability. The center would provide comprehensive information on available programs and services and make referrals to community resources. It would also

provide printed and Internet-based information related to: (1) options for future planning, (2) financial and estate planning, (3) wills and trusts, and (4) advance directives and funeral and burial arrangements.

To date the department has not established the center.

## **OHIO**

In 1999, the Department of Aging partnered with the Ohio Department of Developmental Disabilities and the Developmental Disabilities Council to commission a series of focus groups in 2000 to gain more information about aging caregivers of people with intellectual disabilities and the challenges they face. Among the findings of this review were that:

1. many parents in this situation believe they will outlive their children and have little understanding of how to plan for their child's future;
2. very few parents have made any kind of plans for their own future, instead focusing on their children's needs;
3. the few parents who have made some kind of arrangements for their child's future were concerned that the plans were not done correctly because they did not have access to accurate, understandable information, or to qualified professionals such as attorneys and financial planners; and
4. when the initiative began, the aging services network and Ohio's support system for people with intellectual and developmental disabilities did not interact with and knew very little about each other. (Many families in the developmental disabilities system were unaware of the services and supports available through the aging services network.)

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